Retrolental Fibroplasia

A disease of the retina occurring in premature infants

Prepared by the members of the
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RETROLENTAL FIBROPLASIA is an eye disease which affects some premature babies. Essentially it is a disease of the blood vessels of the retina, which is the inner seeing coat of the eye. If retrolental fibroplasia progresses, the retina becomes detached and a grayish membrane forms behind the lens of the eye which can be seen through the pupil.

This disease is likely to develop in small premature infants. It is comparatively rare in babies with a birth weight over four pounds, and is practically unknown in babies born at the normal time. The frequency of retrolental fibroplasia seems to vary from year to year and also from place to place. It increased from 1942 to 1953 and during that time became the chief cause of blindness among babies.

The condition is usually not present at the time of birth but develops during the first weeks of life. There is, however, a definite critical period; if a baby has reached three months of age without showing any signs of retrolental fibroplasia, the child will not acquire the disease. If, on the other hand, retrolental fibroplasia develops during the critical period it may be six to eight months before the final stage has been reached, and not until then can the vision of both eyes be determined. Fortunately, most of the children who show some ocular changes in their first weeks of life are not severely affected. About seventy per cent of such cases clear up by themselves. The remaining number of children in whom the disease occurs may have little or no useful vision. Some may be able to perceive large objects, while others may be only aware of the difference between darkness and light. Retrolental fibroplasia occurs usually in both eyes, but one eye may be less affected and have relatively good vision while the other may have greatly reduced or no vision.

The final outcome of retrolental fibroplasia can be known when a child reaches eight months of age. The disease then usually remains unchanged. Whatever sight is present will be retained. The acuity of vision ordinarily will not alter in later years but as the child grows he can learn to use his limited sight to a maximum degree.

It seems unlikely that any food deficiency of the mother or any complication during pregnancy causes this disease. There is no evidence that retrolental fibroplasia occurs because of any fault on the part of a mother or father. Neither the type of the milk fed, nor the addition of vitamins, nor the early exposure to light causes retrolental fibroplasia. Recent studies on experimental animals and current medical investigations show an association between the disease and the giving of oxygen, which is sometimes required to keep such a tiny baby alive. The causes for this association between retrolental fibroplasia and

the use of oxygen are not yet entirely clear. It is hoped that further study will give the answer to how the life-saving oxygen can be supplied without running any risk of such a disease.

Retrolental fibroplasia is not a hereditary disease; it is not given by parents to their children. If one child in a family has this eye condition, the brothers and sisters are not more likely to develop the condition than children in any other family.

Some of the *characteristics* of the disease are due to the relatively poor vision of these children. There may be a quick to-and-fro movement of the eyes called nystagmus. Eyes affected with retrolental fibroplasia may be small and appear sunken because they may not grow as much as normal eyes.

Children sometimes develop rather unusual habits during the early years of life. One of these may be pressing or rubbing their eyes. It seems to be an attempt to produce some satisfying sensation by this sort of stimulation. These actions are not desirable, nor are they necessarily harmful to the eyes. Any disturbing habit which a child may develop will tend to disappear as he grows older and gains more confidence in himself and his abilities.

No effective *treatment* is now available, nor seems likely to be so long as the cause of retrolental fibroplasia remains unsolved. However, a great deal of research is going on all over this country and abroad and when effective treatment is discovered, your physician will know about it immediately. The child should be seen regularly by a physician well versed in the disease so that any complication can be detected early. It is better to keep the child under the observation of one qualified physician who thoroughly understands his condition, rather than to change from doctor to doctor.

In some of these children there may occur a complication known as glaucoma, in which there is increased pressure of fluid within the eye. When this happens, the eye generally appears red, waters and is painful. A physician should be consulted immediately.

The *parents' own response* to the situation created by the child's eye condition and their feelings for him play an important part in his whole development. Parents should realize that the child who is blind like any other child needs love, understanding, patience and a feeling of security. In so far as possible during these first years the child should be treated like any normally sighted youngster. The best opportunity for such growth and development is for the child to live with his own family and whenever possible start his school experience by attending a regular nursery school.

It is no longer necessary for parents to try to find the answers by themselves; here are *some ways to find help.* Many states have counseling services and in almost every community there is a social agency prepared to help families with the special guidance and knowledge necessary to insure that their blind children will have maximum opportunities. If the baby is under the medical supervision of a clinic or hospital, the medical social worker who is part of the hospital staff will know ways to work out these plans. Public health nurses and other members of the local health department are familiar with such resources. Social workers in public or private children's agencies can also suggest

where the particular counseling services may be found.

The American Foundation for the Blind, 15 West 16th Street, New York 11, N. Y., has an up-to-date list of the public and private agencies all over the United States that give this particular guidance to parents in the rearing and education of blind children. The National Society for the Prevention of Blindness, 1790 Broadway, New York 19, N. Y., gives similar guidance to parents of partially seeing children.

Because of their unfamiliarity with blindness many parents have profited from exchanging experiences with other parents. Consequently, in numerous places throughout the country discussion groups have come into existence. If you are interested in learning whether there is such a group near your home, inquire of the above agencies.

Much can also be learned from books and pamphlets that have recently been published. A list of some of these follows, with information about where they may be obtained and the cost.

We hope this little folder will be helpful. It was especially prepared to answer many of the questions parents of children with retrolental fibroplasia have in common. If there are matters about this disease which are not mentioned here, your child's physician is the best person to consult.

SUGGESTED READING MATERIAL

A Blind Child, Too, Can Go to Nursery School. American Foundation for the Blind, 15 West 16th Street, New York 11, N. Y.

***A Healthy Personality for Your Child.** U.S. Children's Bureau, 1952. Bulletin No. 337; 20 cents.

Baby and Child Care. Spock, Benjamin, M.D. Duell, Sloan and Pearce, Inc., New York; 1946. Pocket-size edition, 35 cents.

Education of Partially Seeing Children in School Systems. Publication No. 4. National Society for the Prevention of Blindness, 1790 Broadway, New York 19, N. Y.

***Infant Care.** U.S. Children's Bureau, 1951. Bulletin No. 8; 20 cents.

Is Your Child Blind? American Foundation for the Blind, 15 West 16th Street, New York 11, N. Y.

Normal Growth and Development of Children with Visual Handicaps. Mikell, Robert F., M.D. American Foundation for the Blind, 15 West 16th Street, New York 11, N. Y.

***The Preschool Child Who is Blind.** U.S. Children's Bureau, 1953. Folder No. 39; 10 cents.

Toilet Habits: Suggestions for Training a Blind Child. American Foundation for the Blind, 15 West 16th Street, New York 11, N. Y.

***Your Child From One to Six.** U.S. Children's Bureau, 1948. Bulletin No. 30; 20 cents.

* Titles marked with an asterisk should be ordered from the Superintendent of Documents, U. S. Government Printing Office, Washington 25, D. C. Send payment for the pamphlets by check or money order. Be sure to give the full title of the publication and its number with your request.

There is no charge for single copies of the pamphlets produced by the National Society for the Prevention of Blindness or the American Foundation for the Blind.

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